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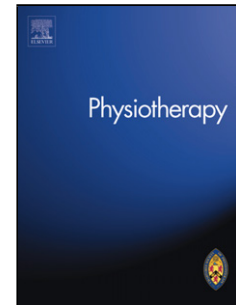
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Title: Participant's experiences of an Education, self-management and upper extremity eXercise Training for people with Rheumatoid Arthritis programme (EXTRA)

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ORIGINAL ARTICLE**Participant's experiences of an Education, self-management and upper extremity eXercise Training for people with Rheumatoid Arthritis programme (EXTRA)****Short title:** Experiences of the EXTRA programmeLindsay M. Bearne, PhD, MSc, MCSP^aVictoria L. Manning PhD MSc BSc (Hons)^aErnest Choy, MB BCh MD, FRCP^bDavid L. Scott, MB BCh MD, FRCP^bMichael V. Hurley, PhD, MCSP^a

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ABSTRACT

Background: The Education, self-management and upper extremity eXercise Trainig for people with Rheumatoid Arthritis programme (EXTRA) is an individualized, upper limb, home exercise regimen supplemented by four supervised, group sessions, a handbook and exercise dairy which improves upper extremity disability and self-efficacy.

Objective and study design: This qualitative interview study explored participants experience of EXTRA to inform development and implementation of EXTRA into practice.

Participants: Adults with Rheumatoid Arthritis who completed EXTRA were purposively sampled to include a range of ages, upper extremity disabilities, self-efficacy for arthritis self-management and attendance at EXTRA sessions.

Methods: Individual, semi-structured interviews were conducted with a single researcher until data saturation of themes was reached. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis.

Results: Twelve participants (10 females; 32-87 years) were interviewed. Four overarching themes were identified: (i) Empowering self-management; (ii) influence of others and (iii) the challenge of sustaining exercise, which resonate with the Social Cognition Theory, and (iv) refining EXTRA: consistent and personalised.

Conclusions: EXTRA enhanced participants' confidence to manage their arthritis independently and was adaptable so it could be integrated with other life commitments. Whilst healthcare professionals, peers and family and friends influenced exercise uptake, sustaining exercise was challenging. Participants desired consistent and continuing contact with a familiar physiotherapist (e.g. via follow-up appointments, digital health technologies) which accommodated individual needs (e.g. different venues, session frequency). Implementation of EXTRA needs to appreciate and address these considerations to facilitate success.

Key words: Rheumatoid Arthritis, the EXTRA programme, qualitative.

INTRODUCTION

Exercise is a key management strategy for improving disability in people with rheumatoid arthritis (RA) [1] but there are few effective and acceptable upper extremity exercise interventions for people with RA.

The 'Education, self-management and global upper extremity eXercise Training for people with RA' programme (EXTRA) comprises a personalised home exercise regimen supplemented with four supervised, group education, self-management and upper extremity exercise sessions, a patient handbook and exercise diary [2]. The programme is underpinned by the Social Cognition Theory (SCT) which proposes that learning occurs in a social context with a dynamic and reciprocal interaction between the person, environment, and behaviour [3]. This theory recognises the importance of social modelling of knowledge and competencies – where individuals develop new behaviours based on what they have witnessed – in motivation, thought and behaviour. According to the SCT, behaviour change is facilitated by a personal sense of control and perceived self efficacy (a person's belief in the ability to perform an action to achieve a desired outcome) is considered a crucial influence on behaviour. The SCT proposes that social modelling, mediated by self efficacy, affects motivation by instilling outcome expectations (beliefs about the consequences of one's actions e.g. alteration in physical function, responses from others or feeling about yourself). In addition to these two key cognitions, the SCT includes goals (self-incentives) and perceived environmental barriers and facilitators. All constructs are proposed to interact throughout behaviour change [3]. Self-efficacy may be influenced through; performance accomplishments or skill mastery such as successfully experiencing an exercise regimen, verbal persuasion e.g. receiving encouragement from others, vicarious experience e.g. observing 'a model person's' progress during exercise (social comparison processes) [3]

and emotional arousal (e.g. not fearing the consequences of exercise (perceived threat) so having the belief that an exercise regimen can be successfully completed). In people with RA, self-efficacy is associated with engagement with self-management, physical activity [4, 5] and medication adherence [6].

Findings from a randomised controlled trial (RCT) show that EXTRA is safe, improves upper extremity disability and self-efficacy and is more cost-effective than usual care [2, 7]. However, clinical implementation demands healthcare interventions are acceptable and meet the needs of the target population, i.e. people with RA [8]. Evaluating this requires a qualitative approach to provide insight into participants' experiences of an interventions [9], which informs refinement and implementation [10]. This qualitative interview study explores participants' experiences of EXTRA and considers refinements to EXTRA.

METHODS

Study Design

This qualitative, semi-structured, interview study received ethical and research governance approval from the London (Dulwich) Research Ethic Committee (08/H0808/118) and King's College, Guy's, St Thomas's and Lewisham Hospital National Health Service Foundation Trusts.

Sampling and Recruitment

All participants enrolled into the RCT (ISRCTN14268051) provided written informed consent to be contacted and interviewed on study completion. Inclusion criteria for the RCT comprised: aged ≥ 18 years with established RA [11] of < 5 years duration, with no contraindications to exercise. Exclusion criteria included: intramuscular or upper extremity intra-articular corticosteroid injections in the previous 4 weeks, upper extremity surgery or

physiotherapy in the previous 6 months and inability to provide written informed consent [2].

A purposive sample of participants were identified to include a range of ages, upper extremity disabilities, self-efficacy for self-management and attendance at the EXTRA sessions [2]. Eligible participants were approached by telephone and invited to attend one interview. Recruitment was stopped when data saturation of themes, defined as no new information obtained from three consecutive interviews, was reached [12].

Participant Characteristics

Sociodemographic and clinical characteristics. Gender, age (years), ethnicity, employment status (employed, retired, student, unemployed) and marital status (single, married, widowed, divorced) were obtained by self-report. Disease duration (years) was obtained from medical records by the direct care team.

Upper extremity disability was estimated using the self-completed Disabilities of the Arm, Shoulder and Hand questionnaire (DASH; range 0-100) [13] and *self-efficacy for self-management* was evaluated using the Arthritis Self-Efficacy Scale comprising 'pain', 'function' and 'other symptoms' subscales (ASES; range 10-100) [14]. *Attendance at the EXTRA supervised sessions* was recorded by the physiotherapist.

Data generation

Eligible participants attended one face-to-face interview lasting approximately 45-minutes, conducted by a single interviewer (VM).

Development of topic guide

Informed by the literature [15,16] and in consultation with experienced, qualitative researchers and clinicians, a semi-structured interview topic guide was developed. Following three pilot interviews, which were not included in the final analysis, the interviewees were

asked to comment on the relevance, acceptability and comprehensiveness of the interview guide. The guide was refined following the pilot interviews and iteratively as insights from ongoing interviews and analyses revealed additional areas of relevance (Appendix). All interviews were audio-recorded.

A reflexive diary and field notes were kept by the interviewer during the study to identify and acknowledge any potential interpretation bias [17,18].

The interviewer was a female Research Associate with qualifications (MSc, BA (Hons)) in health-related disciplines and experience of personal fitness training and exercise prescription for people with long-term health conditions. The interviewer conducted the objective assessments for the RCT but was not involved in randomisation or delivery of EXTRA [2].

Data analysis

Audio-recorded interviews were transcribed verbatim and anonymized using pseudonyms. Transcripts were checked for accuracy against the audio-recordings by the interviewer. Thematic analysis of the interview data was completed using a structured approach (i) familiarisation with text, (ii) coding within the qualitative computer package NVIVO 11 (*QSR International Ltd., Southport, UK*) [19,20], (iii) building categories or themes and interpretation (through content analysis), (iv) identification of thematic framework (v) linking findings with theoretical concepts [21].

Analysis of all transcripts was conducted by the interviewer. A random sample of six transcripts were analysed by a second researcher to corroborate findings. The researchers discussed their findings until interpretive agreement was reached. Themes were also presented to three participants to ensure resonance and plausibility of the themes. Instances of deviant findings were reported [22].

FINDINGS

Participants

Fourteen people were invited for interview although two did not attend the appointment (unknown reasons). Twelve participants were interviewed, between October 2010 and September 2011, (mean \pm Standard Deviation (SD)) 3 ± 2 months following completion of the EXTRA study (Table 1). A good rapport was established between the interviewer and each participant. More women than men (10 women) were interviewed, reflecting the higher prevalence of RA in women [23] and they attended between one and four sessions. Participants were 58 ± 17 years old with moderate upper extremity disability (28 ± 22 DASH points) and self-efficacy for self-management (pain subscale 59 ± 23 points, function subscale 72 ± 25 points, 'other symptoms' 64 ± 21 points).

Themes

Four overarching themes were identified (Table 2):

Empowering self-management

Most interviewees reported enthusiastically that EXTRA was a positive experience which enhanced their ability to manage their arthritis. Attending EXTRA gave some participants new skills, understanding and confidence which lead to a sense of empowerment.

'It builds up your confidence, if you know you are doing the right things for your body, you know what I mean? and then if you see progress, you feel your confidence build up.' (Bella)

Those participants who completed the exercises regularly were happy with the improvement in their upper extremity function and valued knowing which exercises to complete when their symptoms increased.

"I think it's been quite amazing really...to see that change and progress...in my mobility and function in my shoulders." (Kay)

'Sometimes, just thinking about the pain, sometimes when I get up...or I wake up and feel stiff, I thought 'no this is no good, I need to get back to those exercises, because they help.' (Leila)

Learning and understanding

The group discussions helped the majority of participants understand how to integrate exercise into their arthritis self-management. The discussions were participant-led, although moderated by the physiotherapist, so the topics discussed were pertinent to each group. However, discussions sometimes challenged participant's perceptions and assumptions about exercise and helped to alleviate some participants' fears

'my main concern was that, if I was exercising whilst I was in pain, was I actually causing damage to the muscles and joints? The physiotherapist kind of said that, "even if you feel pain, you should still carry on exercising".'
(Catherine)

This learning and understanding was reinforced by participants practising their own exercises in a familiar, reassuring environment.

'At first I was a bit apprehensive of what was going to happen..., you know, with these exercises would [the exercises] be beneficial to me or not? and would they [the exercises] be hard?.....But as it went on, I was fine with it. It made me feel better.And actually, I think, in... that sense, by doing those exercises, it made me ...more determined to ... do other things.' (Ellie)

However, one participant had completed her own research into RA prior to attending EXTRA and was disappointed that the discussions did not extend her knowledge.

'I thought they [the group discussions] were quite basic. I mean, most of the information, you know, I knew.' (Janice)

Another participant voiced that more detail on the potential *'long term effects of inactivity on joints'* (Catherine) would be useful.

One interviewee recommended EXTRA include an individual consultation with the physiotherapist to discuss personal issues and this could allow exploration of understanding and personalised information to be provided prior to EXTRA.

'I think...instead of having [the] group straight away, just maybe a first session to talk...to find out exactly individual problems. How your difficulties [are] affecting you.' (Bella)

Flexibility and independence

Unanimously, participants valued the flexibility offered by exercising at home and often independently modified their exercises to progress or help integrate them into their lives.

"...because I work nights...I take my booklet with me and my straps to work, and if I have...free time, if we're not very busy, and I'm sitting down, I try to do them." (Leila).

'When I first started doing them I used to feel 'Puff! This is hard work but, you know, as I really got into it, they've become easier, alot easier because, obviously, my body was more flexible, they were doing things they were used to doing.and, as I sayI'll add to it, my own ideas [exercise].' (Fiona)

Fiona also adapted her home exercise environment by exercising *'to music 'cause I find it so much nicer.'* (Fiona). This enhanced her enjoyment of her exercises and therefore her satisfaction with EXTRA.

Participants agreed that the handbook supported their learning, and was crucial to their adherence to the exercises. The exercise descriptions and pictures in the handbook provided an *aide-memoire* which reassured some participants. This enabled them to complete their exercises effectively and regularly.

"...you can go back, have a look at your pictures [of the exercises] if you forget what to do..." (Leila)

Only one person considered the handbook unnecessary.

'Generally, when I'm exercising, if I'm gonna do something, I never really think of consulting the handbook. I just do what I normally do' (Andrew)

Setting and working towards personalised goals helped participants independently adapt EXTRA to their needs. Many participants enjoyed recording their progress in the diary and this positively reinforced their effort. This sense of achievement facilitated many participants' adherence to exercise.

"...your goal...you write that in, and you work towards that...and it's a reminder, it's there, so you can turn back to the page and look at it...and, yeah, keep going." (Leila)"

For others, the diary created a sense of obligation to continue with the exercises at home.

"...I had to do it [the exercises] because I had to write it in that book [exercise diary]." (Fiona)

Influence of others

Peers as educators

Many participants spoke positively about the support and learning gained from other group members.

'I was happy, when we come together. It's good to share your problem, because we all got same problem. To share. I know one things works with you but they are not for me, but is still good to know what they doing.'
(Bella)

One participant reported that attending EXTRA eased her feeling of isolation.

"...when you come to something like the classes...you realize that other people have got those problems." (Ellie)

EXTRA also provided an opportunity for group members to compare their disease and exercise performance. This comparison was motivating and reassuring for some participants.

'the main impression was just, wow, it affects so many different people, different ages, um, yeah I wasn't the youngest um, so it was quite reassuring.'
(Janice)

'Well, that person can do this...so I'm going to try and do it. She has pain, I have pain.' (Denise)

Interesting, one participant reported that observing more disabled participants caused her to worry about her own prognosis because *'...if you see people...in very bad condition...you start to worry.'* (Bella).

The Physiotherapist as a supportive facilitator and a knowledgeable professional

Universally, the participants regarded the physiotherapist as a supportive facilitator and a knowledgeable professional who improved their understanding of RA and exercise.

Most interviewees spoke enthusiastically about the physiotherapist and stated that they were essential to their enjoyment and the success of EXTRA and could not be substituted by alternative support strategies.

'If you handed me a booklet and said 'go away and do it. I'd still want to be kind of talked through about what this was doing and why it was important...rather than just 'here's a booklet.' (Kay)

The physiotherapist facilitated participant's transition to independent exercise. Participants commented that the opportunity to practise their own exercises, whilst monitored by the physiotherapist, increased their ability and confidence to adapt, progress and customise their exercises at home. Interviewees found the physiotherapist encouraging, reassuring and motivating, reporting that one therapist *'...had a lot of energy, he was quite, you know, tryin' to kinda motivate us and tryin' to help us understand things.'* (Janice)

The role of family and friends

Most interviewees welcomed the support offered by family and friends and found this influenced their uptake and maintenance of exercise. Family and friends actively prompted some participants to complete their exercises, whilst others provided encouragement.

‘Some people [at work] support you and help you.....when they see you doing your exercises in the corner or [if my family see me] when you wake up early and you exercise, they don’t mind, they support you, they say “oh you’re doing well”.’ (Bella)

Only one participant did not want to share their exercise regimen with their family as she did not want to be regarded as different from other family members.

‘For me, I want to be seen as normal as possible, rather than..... I don’t [like] the idea of doing it, doing it at home.’ (Bella)

The challenge of sustaining exercise

Many participants commented that their exercises were appropriate and helpful but were hard to sustain. Despite having the confidence, knowledge and understanding to adapt and integrate their exercise into their lives; work, other factors (e.g. disease activity) and competing priorities influenced the participants’ ability to complete EXTRA in the long-term.

‘Trying to find time to fit them [the exercises] in, and then, and feeling the stress, “oh, god.....I’ve just got home from work and I’ve still got my bloody exercises to do”.’ (Janice)

Some participants regarded EXTRA as “a good investment for the future.” (Kay) and hoped it would provide long-term benefits. However, one interviewee only attended one session and did not complete the exercises at home as he prioritised other commitments.

‘Why I didn’t take more part in the exercise? because I put other commitments first.’ (Andrew)

One interviewee found that the exercises became boring but recognised that they needed to continue exercising to achieve sustained benefits.

'[It's a] bit of a chore, yeah, but it's like anything, I mean, it's worth persevering if it's going to be, you know, beneficial in the long run.' (Janice)

This suggests that individuals need to adapt or progress their exercises regularly to maintain their interest, enjoyment and motivation to exercise long-term.

Refining EXTRA - consistent and personalised

Overall, participants were satisfied with the delivery and content of EXTRA but suggested refinements to EXTRA when asked for their recommendations.

Participants recommended that staff changes were minimised as a consistent and continuing relationship with the physiotherapist was important to the success of EXTRA.

'The first session, you get to know each other basically, but then the next session, if you have a different physiotherapist, you have to start from the beginning. I prefer to have the same physiotherapist. I know they see lots of people and it's impossible for them to remember everything about you, I understand that. But it was every week so it's easy [for the physiotherapist] to remember.' (Bella)

Some interviewees also desired reassurance and encouragement to sustain exercising via ongoing contact with the physiotherapist. They suggested 'booster' sessions or alternative methods of communication (e.g. digital health technologies) would be useful.

'it might have been useful to, like [have] a, I don't know, a follow-up, or an email or, I don't know, maybe that's why I wanted it to be a larger group, to make a connection with someone so that you can remind each other, "how are you getting on with the exercises?" so somebody else is doing them, it motivates me.' (Catherine)

Most participants valued that EXTRA was held in a local, accessible venue but recognised that a diversity of locations should be offered to cater for the differing needs of people with RA. Some participants stated that they were uncomfortable and embarrassed exercising with the general public and perceived that they were unlikely to receive appropriate

professional support if they exercised outside a healthcare facility, which may influence their views on alternative locations for EXTRA.

‘going to a gym...you feel that you’re...not at that point where other people are.’ (Ellie)

‘A physical instructor [at a gym] would have to know what he’s doing, know about the muscles and joints and how they work, like a physio really, to be able to manage a class with people who have rheumatoid arthritis, to be able to instruct them to do their exercises. For me, I would prefer a physio because she’s in the hospital ...she’s qualified for the job.’ (Leila)

Conversely, some interviewees suggested that EXTRA was held in a ‘school hall, community centre, that sort of thing’ (Janice) because they regarded ‘the hospital is a bit more.... it’s a bit depressing.’ (Denise). One participant suggested that a venue outside a healthcare setting may help integrate exercise into participants’ life and empower self-management.

‘If its [EXTRA] outside a hospitalit would kinda get you into the mind set of thinking, ‘oh well, this isn’t about, you know, hospital and drugs, this is about life and getting on with your life.’ (Kay)

Participant’s wanted EXTRA to fit into their own lives and there was little consensus about the ideal time or frequency of EXTRA sessions. Unsurprisingly, working participants suggested that weekly sessions ‘at the beginning of the day or at the end of the day would have been easier.’ (Catherine). Whereas retired or part-time workers considered the timing of the sessions appropriate.

‘You know, I mean, it worked well because of the days that they [the sessions] were, which was a Tuesday and Thursday, ...that was ideal.’ (Ellie)

Some participants, who usually had high self efficacy for arthritis self-management, required less support and suggested fewer supervised sessions,

“I think one would have been enough...perhaps two sessions...” (Janice)

Conversely, other interviewees would have preferred more weekly sessions.

'I guess six classes would have been good.' (Kay)

DISCUSSION

This is the first study to explore participants' experiences of EXTRA, a novel upper extremity exercise, education and self-management programme. Four overarching themes were identified which suggest that EXTRA enhanced participants' confidence to manage their arthritis independently. EXTRA offered an adaptable exercise regimen which could be integrated into people's lives and improved arm function. Other people influenced participants' exercising and support from peers, family and friends and health professionals were valued, although maintaining exercise was challenging. Participants desired continuing reassurance and contact from a familiar physiotherapist in a local, accessible venue but wanted the timing and frequency of EXTRA to fit around their lives. Recognising and addressing these aspects may aid successful implementation of EXTRA.

Our participants initially expressed concerns that exercising may cause pain and exacerbate disease activity, similar to other research [24,25]. By talking about and addressing these concerns during peer discussions, giving participants the opportunity to witness other people with RA successfully exercise and providing a safe and supportive exercise environment, EXTRA influenced participants understanding, knowledge and confidence in the safety of exercise and empowered them to management their arthritis. Our findings resonate with the SCT, which proposes behaviour change is influenced by a number of key factors such as peoples beliefs about their ability to perform an activity (i.e. self efficacy), the consequences of their actions (i.e. outcome expectations) and their apprehension at performing an activity (exercise) they may perceive as threatening (e.g. emotional arousal). EXTRA was underpinned by the SCT and drew on the models central constructs such as perceived self-efficacy, social modelling, where individuals generate new

behaviours from what they have seen and behaviour change strategies such as goal setting, barrier identification [2, 26]. Our findings support and elucidate the notion that EXTRA enhances self-efficacy for arthritis self-management [2] and its theoretical premise, informed by SCT, that altering people's sense of personal control and perceived self-efficacy for exercise and self-management encourages exercising at home that contributes to improvements in upper extremity disability [27]. The SCT provides a useful framework for interventions promoting exercise and arthritis self-management [28]

EXTRA was personalised and adaptable so changes in symptoms, lifestyle preferences (e.g. time, exercise order) and environment (e.g. listening to music) could be accommodated. Flexibility is important for increasing exercise participation [29]. Our findings concur with Swardh *et al.* [30] who explored the exercise experiences of 18 people with RA and concluded that helping a person adapt and problem solve by promoting self-efficacy was important for exercise maintenance. Further personalisation of EXTRA was desired by participants, including a greater depth and diversity of group discussion, individual and ongoing contact with the physiotherapist either via 'booster sessions' or via smart phone applications, concurring with others [30-33]. Consideration of the potential diversity of learning between group members should be appreciated and addressed to ensure that EXTRA is meaningful for all participants. This may pose practical challenges to the development of EXTRA, which draws on support from peers (social modelling and comparison) and family and friends to enhance exercise participation, and delivery of EXTRA in healthcare systems with limited resources.

Physical activity and exercise is challenging to sustain [34]. Whilst our handbook acted as a prompt and as a record of achievement, consistent with previous studies [35], our interviewees suggested social factors, such as work and physical factors e.g. disease

activity, influenced exercise participation. This agrees with the findings of a previous focus group study, including 75 participants with arthritis, which reported a range of physical (e.g. pain), psychological (e.g. fear), social (e.g. lack of support) and environmental (e.g. lack of facilities) barriers to exercise [16]. Interventions including barrier management influence self-efficacy and physical activity in people with RA [5]. However, our participants reported that sustained exercise was challenging despite barrier management and other behaviour change strategies being integral to EXTRA. There is limited evidence for the effectiveness of specific behaviour change techniques or interventions to promote exercise adherence in arthritis populations [29, 6] and further research is warranted.

Our participants reported guidance from, and the therapeutic alliance with, an expert physiotherapist facilitated their uptake of the EXTRA programme. They stated that written materials alone would be insufficient to support exercise uptake, concurring with previous research [35, 37-39]. Exercising with and observing others with RA, in addition to receiving support from family members and friends, encouraged most participants to change their exercise behaviour, as posited by the SCT. However, the characteristics of group members may influence the effectiveness of peer support [40] and clinicians delivering EXTRA may need to identify the diversity in participant's knowledge and understanding of RA and past exercise experience so that EXTRA can accommodate the needs of all group members and minimise adverse experiences and non-attendance.

This study has a number of strengths: i) we interviewed a range of people with early RA and included those who did not complete EXTRA; thus a diversity of views are explored; ii) coding strategies and data interpretation were corroborated with an independent researcher and the final themes were discussed with some participants to ensure resonance and plausibility of the findings; iii) examples of deviant instances are reported and iv) the

impact of potential researcher bias on the credibility of the findings was considered via a reflexive diary at all stages of the study [41].

However, the interviewer also completed the outcome assessment during the RCT and participants were aware of her professional background, which may have influenced the views participants shared during data generation [42]. Nevertheless, individuals who did not attend all the EXTRA sessions or adhere to the exercises were interviewed and offered refinements for EXTRA, suggesting that this may not be the case.

Data generation ceased after 12 interviews as no new themes were identified during analysis of the final 3 interviews (thematic saturation) [12], however, it is possible that other experiences and insights may be gained if more people were interviewed and different questions posed. Alternative stopping strategies could be employed, such as when the researcher feels they have obtained rich data, which answers the research question whilst telling a persuasive story [43, 44] although if thematic saturation is not achieved, this may impact on the quality of research [45].

Our understanding of the experience of EXTRA would be enhanced by interviewing the physiotherapists who delivered the programme. Anecdotally, the physiotherapists reported that they enjoyed facilitating EXTRA and that it complemented their existing management of people with RA but this needs exploring formally.

This study extends our previous quantitative studies [2, 7] by describing participants experiences of EXTRA. EXTRA enhanced participants' confidence to manage their arthritis independently and was adaptable so it could be integrated with other life commitments. Whilst physiotherapists, peers and family and friends influenced exercise uptake, sustaining exercise was challenging. Participants' desired consistent and continuing contact with a familiar physiotherapist (e.g. follow-up appointments, digital health

technologies) and suggested a range of venues and frequency of EXTRA sessions to accommodate individual needs. Implementation of EXTRA needs to appreciate and address these considerations, which may be challenging to deliver, to facilitate success.

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REFERENCES

1. National Institute for Clinical Excellence, *The Management of Rheumatoid Arthritis in Adults* C79, Dept of Health, 2009: Manchester, UK. p. 1-36.
2. Manning, V.L., et al., *Education, self-management and upper limb eXercise Training in people with Rheumatoid Arthritis (the EXTRA Programme): A randomised controlled trial*. Arthritis Care Research, 2014. **66**(2): p. 217-227.
3. Bandura, A., *Social foundations of thought and action: A Social Cognitive Theory*. 1986, Englewood Cliffs, NJ: Prentice Hall.
4. Huffman, K.M., et al., *Self-efficacy for exercise, more than disease-related factors, is associated with objectively assessed exercise time and sedentary behaviour in rheumatoid arthritis*. Scandinavian Journal of Rheumatology, 2015. **44**(2): p. 106-110.
5. Knittle, K., et al., *Targeting motivation and self-regulation to increase physical activity among patients with rheumatoid arthritis: a randomised controlled trial*. Clinical Rheumatology, 2015. **34**(2): p. 231-238.
6. Van Den Bemt, B.J., H.E. Zwikker, and C.H. Van Den Ende, *Medication adherence in patients with rheumatoid arthritis: a critical appraisal of the existing literature*. Expert Review of Clinical Immunology, 2014.
7. Manning, V.L., et al., *Economic evaluation of a brief Education, Self-management and Upper Limb Exercise Training in People with Rheumatoid Arthritis (EXTRA) programme: a trial-based analysis*. Rheumatology, 2015 **54**(2): p. 302-309.
8. Picorelli, A.M.A., et al., *Adherence of older women with strength training and aerobic exercise*. Clinical Interventions in Aging, 2014. **9**: p. 323.
9. Clarke, A.M. and B. Jack, *The benefits of using qualitative research*. Professional Nurse (London, England), 1998. **13**(12): p. 845-847.
10. Van't Riet, A., et al., *Meeting patients' needs with patient information systems: potential benefits of qualitative research methods*. International Journal of Medical Informatics, 2001. **64**(1): p. 1-14.
11. Aletaha, D., et al., *Rheumatoid Arthritis Classification Criteria - An American College of Rheumatology/European League Against Rheumatism Collaborative Initiative*. Arthritis & Rheumatism, 2010. **62**(9): p. 2569-2581.
12. Francis, J.J., et al., *What is an adequate sample size? Operationalising data saturation for theory-based interview studies*. Psychology and Health, 2010. **25**(10): p. 1229-1245.
13. Hudak, P.L., P.C. Amadio, and C. Bombardier, *Development of an upper extremity outcome measure: the DASH (disabilities of the arm, shoulder and hand) [corrected]*. Upper Extremity Collaborative Gp (UECG). American Journal of Industrial Medicine, 1996. **29**(6): p. 602-8.

14. Lorig, K., et al., *Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis*. Arthritis and Rheumatism, 1989. **32**(1): p. 37-44.
15. Hurley, M.V., et al., *Health beliefs before and after participation on an exercised-based rehabilitation programme for chronic knee pain: Doing is believing*. BMC Musculoskeletal Disorders, 2010. **11**(1): p. 1.
16. Wilcox, S., et al., *Perceived exercise barriers, enablers, and benefits among exercising and nonexercising adults with arthritis: Results from a qualitative study*. Arthritis and Rheumatism, 2006. **55**(4): p. 616-627.
17. Andrews, J., *Using a reflexive diary in social constructionist research into clinical practice*. Journal of Psychiatric and Mental Health Nursing, 1996. **3**(4): p. 267-8.
18. Rolfe, G., *Validity, trustworthiness and rigour: Quality and the idea of qualitative research*. Journal of Advanced Nursing, 2006. **53**(3): p. 304-310.
19. Fisher, M., *Selecting computers for qualitative analysis*, in *IT in Social Sciences: a Students' Guide to the Information and Communication Technologies (ICS)*, H. Millsom, Editor. 1999, Blackwell Publishers: Oxford.
20. Seale, C., *Using computers to analyse qualitative data*, in *Doing Qualitative Research: a Practical Handbook*, D. Silverman, Editor. 1999, Sage Publications: London. p. 154-172.
21. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. Qualitative research in psychology, 2006. **3**(2): p. 77-101.
22. Seale, C., *Accounting for contradictions*, in *The quality of qualitative research*. 1999, Sage Publications: London. p. 73-86.
23. Symmons, D., et al., *The prevalence of rheumatoid arthritis in the United Kingdom: new estimates for a new century*. Rheumatology, 2002. **41**(7): p. 793-800.
24. Law, R.-J., et al., *Perceptions of the effects of exercise on joint health in rheumatoid arthritis patients*. Rheumatology, 2010. **49**(12): p. 2444-2451.
25. Wang, M., et al., *People's Perceptions and Beliefs about their Ability to Exercise with Rheumatoid Arthritis: A Qualitative Study*. Musculoskeletal Care, 2015. **13**(2): p. 112-115.
26. Michie, S., et al., *The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions*. Annals of Behavioural Medicine, 2013. **46** p. 81-95.
27. Bandura, A., *Health promotion by social cognitive means*. Health Education and Behavior, 2004. **31**(2): p. 143-164.
28. Lorig, K.R. and H.R. Holman, *Self-management education: history, definition, outcomes, and mechanisms*. Annals of behavioral medicine, 2003. **26**(1): p. 1-7.

29. Cramp, F., et al., *Health Behaviour Change Interventions for the Promotion of Physical Activity in Rheumatoid Arthritis: A Systematic Review*. Musculoskeletal Care, 2013. **11**(238-30). Swardh, E., G. Biguet, and C.H. Opava, *Views on exercise maintenance: Variations among patients with rheumatoid arthritis*. Physical Therapy, 2008. **88**(9): p. 1049-1060.
31. Schoster, B., et al., *The People with Arthritis Can Exercise (PACE) program: A qualitative evaluation of participant satisfaction*. Preventing Chronic Disease: Public Health Research, Practice, and Policy, 2005. **2**(3): p. 11.
32. Jessep, S.A., et al., *Long-term clinical benefits and costs of an integrated rehabilitation programme compared with outpatient physiotherapy for chronic knee pain*. Physiotherapy, 2009. **95**(2): p. 94-102.
33. Azevedo, A., et al., *Future perspectives of Smartphone applications for rheumatic diseases self-management*. Rheumatology International, 2015. **35**(3): p. 419-431.
34. Manning, V.L., et al., *Are patients meeting the updated physical activity guidelines? Physical activity participation, recommendation, and preferences among inner-city adults with rheumatic diseases*. JCR: Journal of Clinical Rheumatology, 2012. **18**(8): p. 399-404.
35. Pentecost, C. and A. Taket, *Understanding exercise uptake and adherence for people with chronic conditions: A new model demonstrating the importance of exercise identity, benefits of attending and support*. Health Education Research, 2011. **26**(5): p. 908-922.
36. Ezzat, A.M., et al., *The Effects of Interventions to Increase Exercise Adherence in People with Arthritis: A Systematic Review*. Musculoskeletal Care, 2015. © 2014(13): p. 1-18.
37. Der Ananian, C., et al., *Factors that influence exercise among adults with arthritis in three activity levels*. Preventing Chronic Disease, 2006. **3**(3): p. 81.
38. Bossen, D., et al., *Adherence to a Web-Based Physical Activity Intervention for Patients With Knee and/or Hip Osteoarthritis: A Mixed Method Study*. Journal of Medical Internet Research, 2013. **15**(10): p. 55-66.
39. Kaptein, S.A., et al., *Choosing Where to Put Your Energy: A Qualitative Analysis of the Role of Physical Activity in the Lives of Working Adults With Arthritis*. Arthritis Care & Research (Hoboken), 2013. **65**(7): p. 1070-6.
40. Weinberg, R.S. and D. Gould, *Foundatons of Sport and Exercise Psychology*. 2014, Illinois, United States: Human Kinetics.
41. Ortlipp, M., *Keeping and Using Reflective Journals in the Qualitative Research Process*, in *The Qualitative Report*. 2008, Charles Sturt University: Albury. p. 695-705.
42. Jack, S., *Guidelines to Support Nurse-Researchers Reflect on Role Conflict in Qualitative Interviewing*. Open Nursing Journal, 2008. **2**: p. 58-62.

43. Brocki, J.M. and A.J. Wearden, *A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology*. Psychology and Health, 2006. **21**(1): p. 87-108.

44. O'Reilly, M. and N. Parker, '*Unsatisfactory Saturation*': a critical exploration of the notion of saturated sample sizes in qualitative research. Qualitative Research, 2012: p. 1-8.

45. Fusch, P.I. and L.N. Ness, *Are We There Yet? Data Saturation in Qualitative Research*. The Qualitative Report, 2015. **20**(9): p. 1408-1416.

Table 1. Participant characteristics

Participant	Gender	Age(years)	Ethnicity	Employment Status	Marital Status	Disease Duration(months)	Baseline Upper Limb Disability (DASH 0-100)	Baseline 'Pain' Self-Efficacy (ASES 10-100)	Baseline Function Self-Efficacy (ASES, 10-100)	Baseline 'Other Symptoms' Self-Efficacy (ASES, 10-100)	Sessions Attended (n)*
Andrew	Male	79	Black Caribbean	Retired	Married	25	16	18	68	10	1
Bella	Female	46	White	Full-time	Married	20	45	50	77	56	3
Catherine	Female	32	Pakistani	Part-time	Single	15	14	72	76	62	3
Denise	Female	70	Black Caribbean	Retired	Married	20	24	70	71	77	3
Ellie	Female	58	White	Part-time	Married	22	12	70	73	70	4
Fiona	Female	66	White	Retired	Widowed	57	9	88	92	92	4
Greta	Female	87	White	Retired	Widowed	47	70	41	13	47	3
Heidi	Female	65	Black African	Off-sick	Divorced	41	63	37	X	55	3
Ian	Male	39	White	Full-time	Married	65	8	92	99	72	4
Janice	Female	45	White	Full-time	Single	12	11	X	88	72	2
Kay	Female	46	White	Off-sick	Divorced	13	48	42	41	68	3
Leila	Female	61	Black Caribbean	Part-time	Single	59	16	64	90	88	4

DASH: Disabilities of the Arm, Shoulder and Hand questionnaire; ASES: Arthritis Self-Efficacy Scale; *Maximum of 4 sessions

Table 2 Themes

Theme	Subtheme
Empowering self-management	Learning and understanding
	Flexibility and independence
Influence of others	Peers as educators
	The Physiotherapist as a supportive facilitator and a knowledgeable professional
	The role of family and friends
The challenge of sustaining exercise	

Refining personalised	EXTRA-consistent	and	
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